Development of the Lifespan Transition Clinic (LTC): A collaboration between inter-professional specialty clinic and community partners in Oregon

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Clinical Need:

- **79% of Oregon families with special health care needs (SHCN) do not receive adequate health care transition services[1]**
- **The Child Development & Rehabilitation Center (CDRC) at Oregon Health & Science University (OHSU) provides inter-professional services for families from Oregon and SW Washington who experience SHCN**
- **Provider surveys show lack of time during specialty clinic visits to address transition**
- **Limited adult providers, variation in family readiness to start the transition process, delayed start to transition planning, and inadequate information of community resources exist[2]**
- **Support to achieve goals is often fractured across agencies[3]**

LTC Clinic goals

Providers: Occupational Therapy and Social Work

1. **Provide health care transition support for families age 12+ who visit our inter-disciplinary clinics and have chronic health, developmental, or behavioral conditions**
2. **Help families identify transition readiness, prioritize transition goals, and facilitate the steps to successfully transition to an adult system of care**
3. **Connect the individual and their family with community partners (i.e. health providers, education system, developmental disabilities service coordinator) to coordinate care and transition goals**
4. **Support development of current care plan, emergency care plan and provide support and resources needed for identification of adult primary care provider, including contact information for consultation from pediatric provider**

Barriers

- **Travel Time:** time it takes family to come up to clinic visit in Portland, OR
- **Insurance:** coverage for follow-up appointments with OT and SW
- **Community supports:** knowing what supports are available in client's area
- **CARE COORDINATION:** Who manages all the family's services? Who helps implement transition plan?

Evaluation:

Mental Health Assessment

Canadian Occupational Performance Measure (COPM)

Step 1: Identification of Occupational Performance Issues
Step 2: Rating importance on a scale of 1 (low) -10 (high) for each activity
Step 3: & 4: Identify performance (P) ratings on a scale of 1 (low) -10 (high) and satisfaction with performance (S) 1 (low) -10 (high)

Occupational Performance Problem	P1	S1
1. Washing hands/hygiene	2	1
2. Finding adult MD (specialties)	1	1
3. Find day program/activities	5	4
4. Leisure activities	1	1
5. Mood affecting daily activities	4	1
6. Finding housing	1	1

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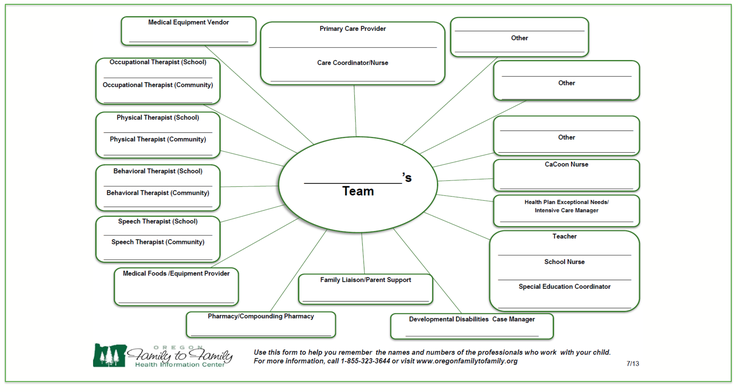

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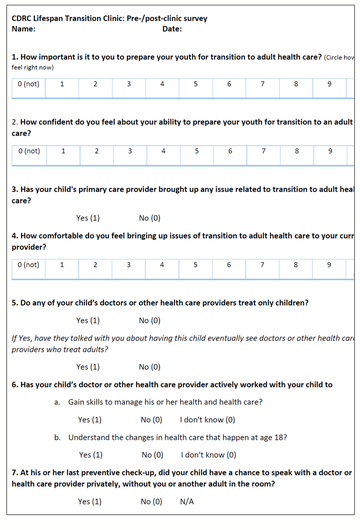

CDRC Lifespan Transition Clinic: Pre-/post-clinic survey
Name: Date:

1. How important is it to you to prepare your youth for transition to adult health care? (Circle how
feel right now)

0 (not) 1 2 3 4 5 6 7 8 9

2. How confident do you feel about your ability to prepare your youth for transition to an adult
care?

0 (not) 1 2 3 4 5 6 7 8 9

3. Has your child's primary care provider brought up any issue related to transition to adult heal
care?

Yes (1) No (0)

4. How comfortable do you feel bringing up issues of transition to adult health care to your curr
provider?

0 (not) 1 2 3 4 5 6 7 8 9

5. Do any of your child's doctors or other health care providers treat only children?

Yes (1) No (0)

*If Yes, have they talked with you about having this child eventually see doctors or other health car
providers who treat adults?*

Yes (1) No (0)

6. Has your child's doctor or other health care provider actively worked with your child to

a. Gain skills to manage his or her health and health care?

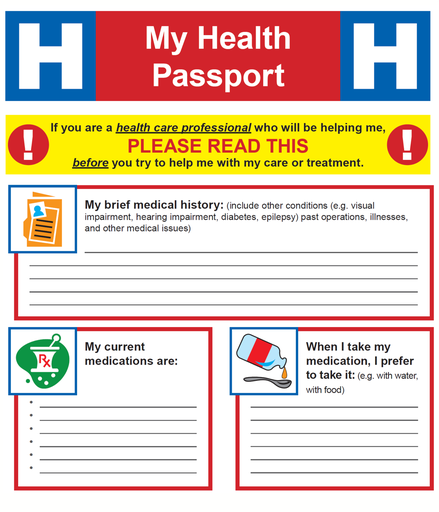
Yes (1) No (0) I don't know (0)

b. Understand the changes in health care that happen at age 18?

Yes (1) No (0) I don't know (0)

7. At his or her last preventive check-up, did your child have a chance to speak with a doctor or
health care provider privately, without you or another adult in the room?

Yes (1) No (0) N/A



Connection to community: Oregon Center for Children and Youth with Special Health Care Needs (OCCYSHN):

- **Contracts with 34 counties with community health teams to develop Shared Plans of Care (SPoC)**
- **Contract requires 20% SPoC include transition goals**
- **Community teams request input from LTC for health care transition goals**

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ACTION PLAN
(Sample)

- The first goal of the team should be one that is identified by the family as a priority.
- If the child/youth is aged 12 or older, include a minimum of one goal focused on the transition to adult healthcare.

SHARED GOAL	Who?	Is doing what?	By when?
Goal: (2/16/18) Establish care with adult neurologist	This person Dr. W. (Pediatric Neurologist)	Will take this action Provide policy on transition to adult neurologist (age of transfer)	By this date 3/1/18 (date completed)
	This person J. (CaCoon nurse)	Will take this action Provide list of adult neurologists within young adult's insurance network	By this date 4/1/18 (date completed)
	This person S. (Parent) and T. (young adult) and Dr. Z. (primary care physician)	Will take this action Complete portable medical summary	By this date 5/1/18 (date completed)
(date resolved)	This person S. & T	Will take this action Attend first appointment with new adult neurologist	By this date 6/30/18 (date completed)

Feedback:

From parent (1-month post clinic call): ***"right now she feels that T's transition needs are being met and is excited about T's new opportunities. Mother reports that* CAre COordinatiON (*CaCoon) nurse checks in with her on a monthly basis and is available for support"***

From CaCoon nurse*: "putting together the SPoC takes a great deal of time and this process helped reduce the overall workload in identifying stakeholders and transition goals for the SPoC. She likes the 'warm hand-off' from our team to hers. She shared 'this may be the most exciting thing I do in my career'."*

Future plans:

- **Outcome measures**
- **Expanding model to partner with Coordinated Care Organizations (CCOs) and brokerages**
- **Clinic-Community Advisory Board**
- **Self-advocate in clinic**
- **LEND Training in community outreach**

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